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INTRODUCTION: Breast cancer survivors are at elevated risk for developing a new breast cancer compared to healthy women, and are at considerable risk for breast cancer recurrence. According to the American Society of Clinical Oncology, survivors should undergo careful breast cancer surveillance including annual mammography and breast self-exam. However, studies indicate that breast cancer surveillance among African American survivors, particularly mammography, is low, especially given the higher risk of survivors as a group. The promotion of breast cancer surveillance among African American survivors is an area that deserves special attention as cancers detected early are more treatable. One promising strategy is the adaptation of a peer-led intervention developed to increase screening among healthy African American women. The objectives of the current study are: 1) to evaluate the impact of a peer-led intervention on breast cancer surveillance intention and adherence among African American breast cancer survivors through a randomized controlled trial; and 2) to investigate the mediational pathways through which the peer-led intervention impacts surveillance intention and adherence. 409 participants will be recruited and randomized over the course of the study. Participants will be African American women age 20-74 years and diagnosed with Stage I, II or III breast cancer who previously participated in an ongoing parent project and are at least 3 months post-treatment. Once informed consent is obtained, participants will be contacted via telephone to complete a baseline interview assessing sociodemographic information, breast cancer surveillance intention and adherence, and attitudinal/cognitive variables. Participants will then be assigned to either the survivor surveillance intervention condition or control condition and those in the intervention condition will participate in the intervention. One month following the intervention, participants in both conditions will complete a telephone interview to assess breast cancer screening adherence and changes in attitudinal/cognitive variables from baseline to post-intervention. Fourteen months after the intervention, women in both conditions will be contacted again in order to assess surveillance intention and adherence.

BODY: The approved statement of work for the current study is included as Appendix A. Although the performance period began in June 2003, Initial DOD Human Subject Protection Review was completed and approval received in November 2004. Necessary amendments to the protocol to improve recruitment efforts that were approved in December 2006. In June 2007, a one-year no-cost extension was granted.

Tasks completed in the past year are described below.

A. Task 2: Recruit participants, conduct baseline assessment interview for randomized controlled trial evaluating peer-implemented survivor surveillance intervention, and conduct intervention

Since June 2006, 16 women have been recruited under the current protocol and four “Survivors in Spirit” presentations (intervention programs) were conducted. In total, data for 60 women are available.

B. Task 3: One-month follow-up assessment interviews

Since June 2006, 15 women have completed 1-month follow-up interviews. In total, data for 40 women are available.

C. Task 4: Fourteen-month follow-up assessment interviews.

Women recruited since June 2006 are not yet due for their 14-month follow-up. In total, data for 31 women are available.

D. Task 5: Interim data analyses, report and presentations

Preliminary findings based on a subset of participants across several study sites show that from baseline assessment to 1 month follow-up after attending an intervention presentation, survivors in the

intervention group demonstrated a 7% increase in knowledge about recurrence and post-treatment surveillance while there was no increase (0%) in knowledge among those in the control group. Additionally, results of the randomized controlled trial showed that, from baseline assessment to 1-month follow-up, the intervention group reported an increase in their perception of the benefits of post-treatment surveillance while the control group actually demonstrated a decrease in perceived benefits. The intervention group also reported stronger intention to participate in necessary mammography screening, physical exams, and BSEs from baseline to 1-month follow-up while intention to participate in physical exams decreased in the control group over the same time period. We also collected evaluation data on intervention presentation quality. Among survivors in the intervention condition, 100% of those who attended a presentation reported that it was well-organized and that they felt good about their ability to use what they learned.

KEY RESEARCH ACCOMPLISHMENTS: Key research accomplishments since June 2006 include: 1) the publication of a manuscript based on formative work in the development of the intervention, 2) the recruitment of 16 survivors for study participation and completion of baseline and 1-month follow-up interviews, and 3) successful completion of four intervention programs.

REPORTABLE OUTCOMES: Data obtained through formative work was published (article attached): **Thompson, H.S.,** Littles, M., & Coker, C. (2006). Post-treatment breast cancer surveillance and follow-up care experiences of African-American and African-Caribbean breast cancer survivors: An exploratory qualitative study. *Cancer Nursing*, 29 (6).

Semi-structured key informant interviews were conducted in order to explore the following: 1) the extent of post-treatment surveillance information provided to or obtained by survivors of African descent; 2) the actual follow-up care received by survivors; and 3) factors that are either motivators of or barriers to care. Participants were 10 Black (African American and African Caribbean) breast cancer survivors between 38 and 63 years of age. Survivors reported a number of factors that motivated them in obtaining follow-up care: a desire to maintain good health, concern about recurrence, support from healthcare providers, familial relationships, relationships with other survivors, and religious/spiritual faith. Survivors also reported barriers to care: fear of recurrence, low support from family and friends, lack of information about post-treatment follow-up care, and medical care costs. These issues were incorporated into the training curriculum for interventionists.

CONCLUSIONS: Preliminary findings suggest that the exposure to the post-treatment surveillance intervention results in increases in knowledge about recurrence and post-treatment surveillance, perceptions of the benefits of post-treatment surveillance, and stronger intentions to participate in necessary mammography screening, physical exams, and BSEs. Preliminary findings also suggest that intervention quality is high, based on favorable participant feedback and evaluation. During the no-cost extension year, we will focus on continuing follow-up interviews as well as conducting additional data analyses.

Appendix A. Approved Statement of Work

Task 1: Study start-up (Months 1-5)

- a. Hire and train research assistant and data entry clerk
- b. Collaborate with co-investigators and consultants to review assessment strategies and tailoring of the survivor surveillance intervention
- c. Train peer interventionists (recruited from the ongoing Witness Project of Harlem)
- d. Pilot test and refine unstandardized measures
- e. Prepare data entry and participant tracking systems

Task 2: Recruit participants, conduct baseline assessment interview for randomized controlled trial evaluating peer-implemented survivor surveillance intervention, and conduct intervention (Months 6-30)

- a. Review database of parent project to identify eligible breast cancer patients
- b. Recruit 409 patients for randomized controlled trial via telephone and mail informed consent forms
- c. Administer baseline assessment interview for randomized controlled trial via telephone upon receipt of signed informed consent forms (expected total of baseline interviews=409)
- d. Randomize participants
- e. Mail incentives (\$20 money orders) for participation
- f. Develop schedule of survivor surveillance intervention presentations (expected total of presentations=14)
- g. Begin data entry and management

Task 3: One-month follow-up assessment interviews (Months 8-30)

- a. Contact participants via telephone to administer one-month follow-up assessment interviews (expected total of one-month follow-up interviews=389 with 5% attrition from baseline)
- b. Mail incentives (\$20 money orders) for participation
- c. Continue data entry and management

Task 4: Fourteen-month follow-up assessment interviews (Months 21-45)

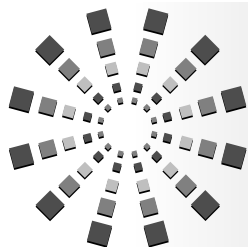
- a. Contact participants via telephone to administer 14-month follow-up assessment (expected total of 14-month follow-up interviews=311 with 20% attrition from 1-month follow-up)
- b. Mail incentives (\$20 money orders) for participation
- c. Continue data entry and management

Task 5: Interim data analyses, report and presentations (Months 22-27)

- a. Work with co-investigators and consultants to conduct preliminary analyses for report
- b. Present preliminary results at scientific meetings

Task 6: Final data analyses, report and presentations (Months 45-48)

- a. Work with co-investigators and consultants to conduct analyses for report
- b. Present results at scientific meetings
- c. Prepare manuscripts for publication



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Posttreatment Breast Cancer Surveillance and Follow-up Care Experiences of Breast Cancer Survivors of African Descent

An Exploratory Qualitative Study

KEY WORDS

Breast cancer recurrence

Breast cancer surveillance

Breast cancer survivors

Racial/ethnic disparities

Breast cancer survivors are at considerable risk for breast cancer recurrence and at higher risk of developing a new breast cancer compared with women never diagnosed. It is recommended that survivors undergo careful breast cancer surveillance as cancers detected early are more treatable. However, data indicate that surveillance among African American survivors, particularly mammography, is lower than that of white survivors. There is little published work focusing on general experiences of posttreatment breast cancer surveillance among survivors of African descent. In the current qualitative pilot study, key informant interviews were conducted in order to explore the following: (1) the extent of posttreatment surveillance information provided to or obtained by survivors of African descent; (2) the actual follow-up care received by survivors in the past year; and (3) factors that are either motivators of or barriers to care. Participants were 10 African American and African Caribbean breast cancer survivors. Survivors reported a number of factors that motivated them in obtaining follow-up care: a desire to maintain good health, concern about recurrence, support from healthcare providers, familial relationships, relationships with other survivors, and religious/spiritual faith. Survivors also reported barriers to care: fear of recurrence, low support from family and friends, lack of information about posttreatment follow-up care, and medical care costs. These results represent formative work that may inform similar studies examining factors in breast cancer surveillance and follow-up care in larger samples of survivors of African descent.

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Breast cancer survivors are at considerable risk for local breast cancer recurrence. Local recurrence rates among breast cancer patients diagnosed primarily with in situ, stage I or stage II disease and receiving surgical treatment and adjuvant therapy are reported at 5% to 10% at 5-year follow-up and 10% to 15% at 10-year follow-up.¹⁻⁵ Breast cancer survivors are also 2 to 6 times more likely to develop a second primary breast cancer in the contralateral breast compared with women in the general population.^{6,7} Thus, breast cancer survivors represent a high-risk population for whom careful breast cancer surveillance and follow-up care is a priority. Evidence indicates that locally recurrent or contralateral breast cancers found at an early stage, specifically those that are noninvasive or characterized by smaller tumor sizes, are associated with a better prognosis compared with more advanced cancers.^{8,9}

Routine screening, particularly mammography and physical examination, has been found to detect local recurrences and contralateral breast cancers at earlier stages,⁹⁻¹² but data suggest that breast cancer survivors underuse surveillance modalities, particularly mammography. Across several recent studies, 22% to 45% of breast cancer reported no mammogram during intervals ranging from 2 to 4 years.^{13,14} In one study, African American (AA) survivors were approximately half as likely to have a mammogram compared with white survivors.¹⁵ It has also been reported that duration of medical follow-up care for AA survivors was significantly shorter than that of white survivors (53 vs 65 months, respectively).¹⁶ These findings suggest that the promotion of posttreatment breast cancer surveillance among survivors of African descent is an area warranting special attention.

Surprisingly, there is little published work on predictors of posttreatment breast cancer surveillance and follow-up care among breast cancer survivors of any ethnicity or race. Two models may guide the investigation of these predictors. The first is Andersen's Behavioral Model for Health Services Utilization (BMHSU),¹⁷ which outlines the role of population characteristics, the healthcare system, and the external

environment in explaining and predicting health behaviors. In the current research, we have focused on population characteristics: (a) predisposing factors (eg, demographic characteristics, health beliefs), (b) enabling resources (eg, social relationships, access to healthcare, ability to pay for healthcare), and (c) need factors (eg, perceived and evaluated need, such as physician recommendation) (see Figure 1).

There is evidence that BMHSU factors are predictors of surveillance and follow-up care among breast cancer survivors. For example, physician recommendation, a need factor described by the BMHSU, is associated with participation in mammography among survivors.¹⁴ Enabling factors are also associated with mammography use among survivors, such as employment status and receiving treatment at a breast center.¹⁴ Predisposing factors that have been identified are largely limited to diagnostic and treatment variables, such as method of initial cancer detection, stage of diagnosis, and type of treatment received.^{13,14,18} There are no published data on role of attitudinal predisposing factors that influence surveillance among breast cancer survivors. However, such factors have been reported to be associated with mammography screening among healthy AA women in the general population and these findings may provide insight into mammography among survivors. Among AA women in the general population, breast cancer knowledge was significantly associated with past adherence to mammography as well as intention to have a mammogram.¹⁹⁻²² Perceived benefits of mammography have also been reported to be salient among AA women, such as obtaining peace of mind and the early detection of cancer.²³ Some perceived barriers were also significantly more likely to be reported by AA women compared with whites, such as increased cancer-related worry and fear of radiation exposure during a mammogram.²⁴⁻²⁶

The second model that may guide the investigation of predictors of surveillance and follow-up care is Baldwin's Afrocentric model for describing AA women's participation in breast and cervical cancer screening.²⁷ A primary component of this model is the African worldview: the extent to which

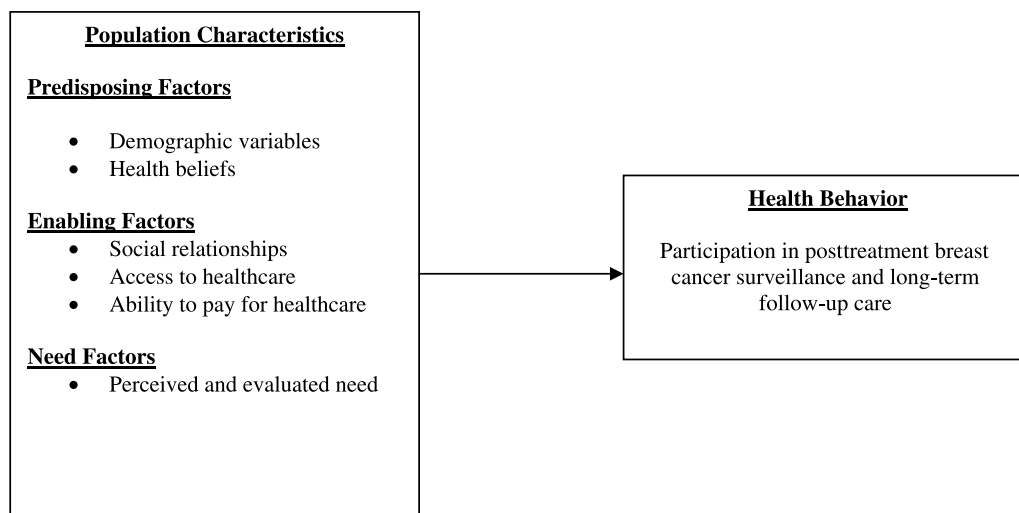


Figure 1 ■ Andersen's Behavioral Model for Health Services Utilization.

one's cultural traditions and values influence daily life. Based on this Afrocentric model, it is plausible that sociocultural factors salient among survivors of African descent may be associated with surveillance. One such factor is collectivism, or the belief that members of one's cultural group and family play a major role in shaping individual behavior, including health behaviors such as mammography.²⁸ Evidence for the role of collectivism in breast cancer-related preventive care was reported by Hughes et al,²⁹ who found that familial interdependence influenced participation in genetic testing for breast cancer risk. A second sociocultural factor encompasses religious and spiritual beliefs, the salience of which is well-documented in African cultures. Mitchell et al³⁰ found that AA women in the general population were more likely to hold religious beliefs related to breast cancer. Additionally, God locus of control and spiritual locus of health control were associated with adherence to breast cancer screening in undiagnosed AA samples.^{31,32} Such sociocultural factors may also influence surveillance among breast cancer survivors.

The current study attempted to address the gap in the literature on posttreatment breast cancer surveillance and follow-up care experiences of breast cancer survivors of African descent. Both the American Society of Clinical Oncology (ASCO) and the National Comprehensive Cancer Network (NCCN) recommend that following primary treatment, breast cancer survivors participate in annual mammography and a schedule of frequent physical examinations and symptom histories.^{33,34} ASCO also recommends monthly breast self-examination (BSE) and regular pelvic examination and Papanicolaou test.^{33,34} In the current qualitative pilot study, key informant interviews were conducted with AA and African Caribbean (AC) breast cancer survivors to explore the following: (1) the extent of posttreatment surveillance knowledge among survivors; (2) the actual follow-up care received by survivors in the past year; and (3) factors that serve as either motivators of or barriers to care. Motivators and barriers were further categorized as predisposing, enabling, and need-related according to the BMHSU.

■ Methods

Participants

Participants were 10 AA/AC female breast cancer survivors residing primarily in the New York City area. Eligibility criteria included self-identification as black or of African descent, being age 20 years or older, completion of primary treatment of breast cancer at least 1 year before study participation (primary treatment was defined as any combination of surgery, radiotherapy and chemotherapy), and having a single breast cancer diagnosis with no diagnosis of recurrent or contralateral breast cancer.

Assessment

Participants were first asked questions about sociodemographic variables, including age, ethnicity, and education

level. They were also asked about their breast cancer treatment, including time of diagnosis, type of primary treatment, and the date primary treatment ended. All participants completed key informant interviews that were structured according to a model outlined by Wengraf.³⁵ In this model, semistructured in-depth interviews are used to build and test descriptive and explanatory models of social and psychological experience. Features of a semistructured depth interview include the following: (1) it is fundamentally a research interview designed for the purpose of expanding knowledge; (2) as a research interview, it is a unique type of conversational interaction influenced by both interviewer and interviewee characteristics; (3) it is designed with interview questions prepared in advance but open in such a way that requires some interviewer improvisation during the interview; and (4) it is in-depth in the sense that it assumes that social and behavioral phenomena are more complex than they often appear. The structure of a semistructured depth interview is guided by the CRQ-TQ-IQ model described by Wengraf.³⁵ In this model, a central research question (CRQ) is identified and explicated through several theory questions (TQs) to which responses are sought. Such TQs are conceptual-framework-dependent and formulated in theoretical language. Theory questions guide the development of interview questions (IQs) that represent the operationalization of TQs in language that is appropriate for use with study participants. To obtain information relevant to a TQ, interviewees are asked to respond to IQs.

The CRQ of the current study was "What is the experience of posttreatment breast cancer surveillance and follow-up care among breast cancer survivors of African descent?" This CRQ was followed by 3 broad TQs: (1) What is the extent of AA/AC survivors' knowledge of surveillance and follow-up care guidelines? (example IQs: After your treatment, what were you told about the long-term follow-up care you need? What was your understanding of the purpose of long-term follow-up care?); (2) In what type of surveillance and follow-up care do AA/AC survivors participate? (example IQs: Who do you see for your long-term follow-up care? What follow-up care have you received in the past year?); (3) What factors serve as either facilitators of or barriers to AA/AC survivors' follow-up care? (example IQs: What has motivated you to get the care you have received so far? How much does your family motivate you? What, if anything, has kept you from getting long-term follow-up care? How much do medical costs keep you from getting care? How does religious or spiritual faith affect your follow-up care?). Participants were asked to base their answers on their own experience as well as their observations of the experiences of other AA/AC survivors. In addition to responding to TQs and IQs, participants were also asked to separately respond to 3 close-ended items: (1) "I get enough information about breast cancer recurrence (getting breast cancer again) at my follow-up visits"; (2) "My emotional and psychological concerns are addressed at my follow-up visits"; and (3) "I feel reassured by my follow-up visits." Response options were based on a Likert-type scale from 1 (*strongly disagree*) to 4 (*strongly agree*).

Study Design, Procedures, and Analysis

The current study was exploratory, qualitative, and was intended to represent formative work in an understudied area: posttreatment breast cancer surveillance and follow-up care among breast cancer survivors of African descent. Participants were recruited through breast cancer patient support groups as well as volunteer pools of cancer education and outreach programs. Announcements were made at meetings of these groups by study staff, and survivors who expressed interest in participating in the study provided their contact information and were later contacted by staff. Eligibility was confirmed at that contact. Once eligible participants were identified and informed consent obtained, interviews were conducted either over the telephone or in person by trained, ethnically matched interviewers. All interviews were audiotaped and lasted between 30 and 60 minutes. Interviews were then fully transcribed. An open-coding strategy was used to identify common concepts across participant responses and to develop categories of responses for each TQ. Coding was facilitated by the Ethnograph V5.08 software package. Participant recruitment was ended after the 10th participant based upon findings that emerged during ongoing data analysis. These findings suggested that theoretical saturation had been reached such that no new or relevant dimensions were emerging from the data, and additional interviews from our potential pool of participants would not have yielded new insights.³⁶

■ Results

Participant Characteristics

Table 1 summarizes participants' background information, including information about their breast cancer treatment and follow-up care. Participants were between 38 and 63 years (mean age = 50.2; SD = 8.4). Five participants identified as AA, 4 identified as AC, and 1 self-categorized as both. In terms of breast cancer history, participants were between 1 and 6 years posttreatment (mean = 3.0 years; SD = 1.8). Nine participants were treated surgically, 9 underwent adjuvant radiation or chemotherapy (1 participant received chemotherapy as primary treatment), and 7 continued to take some type of hormonal therapy once primary treatment ended.

TQ1: What is the Extent of AA/AC Survivors' Knowledge of Surveillance and Follow-up Care Guidelines?

All participants except one reported that they were provided with specific recommendations about follow-up care after primary treatment ended. The most common recommendation reported from any physician with whom participants had contact was to increase the number of physician visits over the course of a year. More than half of the participants were advised to schedule physician visits every 3 to 6 months

❁ **Table 1 • Participant Characteristics, Treatment Information, and Physicians Providing Follow-up Care**

	n
Age	
35–49 years	5
50–59 years	3
≥60 years	2
Education level	
<High school	2
High school or GED	4
Associate's, Bachelor's, or graduate degree	4
Time since end of primary treatment	
1–2 years	5
3–4 years	3
5–6 years	2
Type of surgery	
Mastectomy	4
Breast-conserving surgery	5
Adjuvant therapy	
Radiation therapy	3
Chemotherapy	4
Both radiation and chemotherapy	2
Hormonal therapy (eg, Tamoxifen, Nalvodex)	7
Reported specialty of physicians seen for breast cancer surveillance	
Oncologist	5
Surgeon	6
Radiologist	4
Primary care physician	5
Gynecologist	5

immediately after treatment and then every 6 to 12 months as posttreatment time progressed.

TQ2: In What Type of Surveillance and Follow-up Care do AA/AC Survivors Participate?

In this sample, the mean number of physician visits in the past year was 6 (SD = 3.5; range = 2–15 visits). In these analyses, physician visits served as a proxy for symptom history discussions. When asked what type of physicians provided their follow-up care, most participants reported seeing several medical specialists, including oncologists, surgeons, primary care physicians, gynecologists, and radiologists. These data are presented in Table 1. The frequencies of other breast cancer surveillance strategies are presented in Table 2. The majority of participants (70%) both reported at least 2 physical examinations in the past year and were adherent to ASCO guidelines for physical examination. Although only 2 participants reported receiving specific mammography recommendations, almost all participants reported a mammogram in the past year. Similarly, most participants did not report receiving specific information about BSE but all reported practicing BSE, with approximately half practicing BSE monthly and the other half either overpracticing or underpracticing. Almost all participants reported a pelvic examination and Papanicolaou test in the

past year. Half of the participants also reported receiving extensive cancer surveillance, with the most common ones being blood tests, bone scans, and sonograms. Other tests included MRI, x-ray, PET scan, and CT scan.

Interestingly, most participants mentioned dietary change (eg, decrease in consumption of high-fat foods) and maintenance of a healthy weight as part of recommendations that they received regarding posttreatment follow-up care. However, there was some indication that although participant interest in dietary change was high, the information they were provided was too general. As one participant expressed:

One of the things that I find is a problem though is... it's trying to get a balance with nutrition and um, and linking it with oncology, you know, and I don't think it's readily available. You really have to go out and seek that part of it to me that is a part of the care or should be a part of the care. And to me it's not in there as much as it should be.

This statement represents the general consensus among participants that diet and nutrition as an area of posttreatment wellness is important and about which more specific information is desired.

TQ3a: What Factors Serve as Motivators of AA/AC Survivors' Follow-up Care?

Survivors reported a number of motivating factors in obtaining follow-up care: a desire to maintain good health, concern

about recurrence, support from healthcare providers, familial relationships, relationships with other survivors, and religious or spiritual faith. These motivating factors were further categorized as predisposing, enabling, or need-related (see Figure 2).

DESIRE TO MAINTAIN GOOD HEALTH

The desire to stay healthy, live a healthy life, or to live was most often cited first as a motivating factor in obtaining follow-up care. Follow-up care was often associated with early recurrence detection, and early detection was widely viewed as a key component of maintaining one's health. This is indicated in the following participant's statement:

I'm a firm believer that through early detection, you're going to alleviate a lot of problems. So, I think that continuous care is needed so in case there is a problem developing, we could, you know, address it early.

CONCERN ABOUT BREAST CANCER RECURRENCE

Concern about recurrence was cited as a factor that motivates participation in follow-up care. Participants indicated that such concern motivates them to obtain care because it fosters vigilance about health. For example:

I'm concerned that the breast cancer might come back. But that will make me go more to get the care. But at the same time, you know, I try to be mindful that it's not a journey that I would want to go on again because the second time around is definitely going to be worse than the first time. So, you know, I do try to do what's necessary, in order to avoid that experience again.

As this statement indicates, concern may be fueled by the memory of the first diagnosis and subsequent treatment, as well as anticipation of greater difficulty managing a second diagnosis. Interestingly, when asked about their perception of their recurrence risk, half of the participants stated that they believed their chances of getting cancer again were "none" or "zero." The other half acknowledged the possibility, stating "50/50" or that they weren't sure.

SUPPORT FROM HEALTHCARE PROVIDERS

Physician recommendation was often endorsed as a motivator of follow-up care participation. Recommendation was often not distinguished from personalized encouragement from physicians and participants' perceptions that their physicians genuinely cared about them as individuals. Participants indicated that they were more likely to keep appointments because they felt that their physicians were kind, trusted that their physicians acted in their best interests, and felt that their physicians took a personal and professional interest in them both physically and psychologically. For example:

To be honest, my doctor, his concern motivated me. He cares so much, I need to care. He showed that he cared so much.

❁ Table 2 • Participant-reported Breast Cancer Surveillance in the Past Year	
Frequency of Tests	n
Tests included in ASCO guidelines	
Physical examination	
1	3
2	4
≥3	3
Mammogram	
0	3*
1	7
Pelvic examination/Papanicolaou test	
0	2
1	7
2	1
BSE	
Daily	3
Monthly	6
Every other month	1
Other surveillance tests	
Blood tests	3
Sonogram	2
Bone scan	2
Other	5

ASCO indicates American Society of Clinical Oncology; BSE, breast self-examination.
*Two of these participants reported having an upcoming appointment for a mammogram and the third reported double mastectomy.

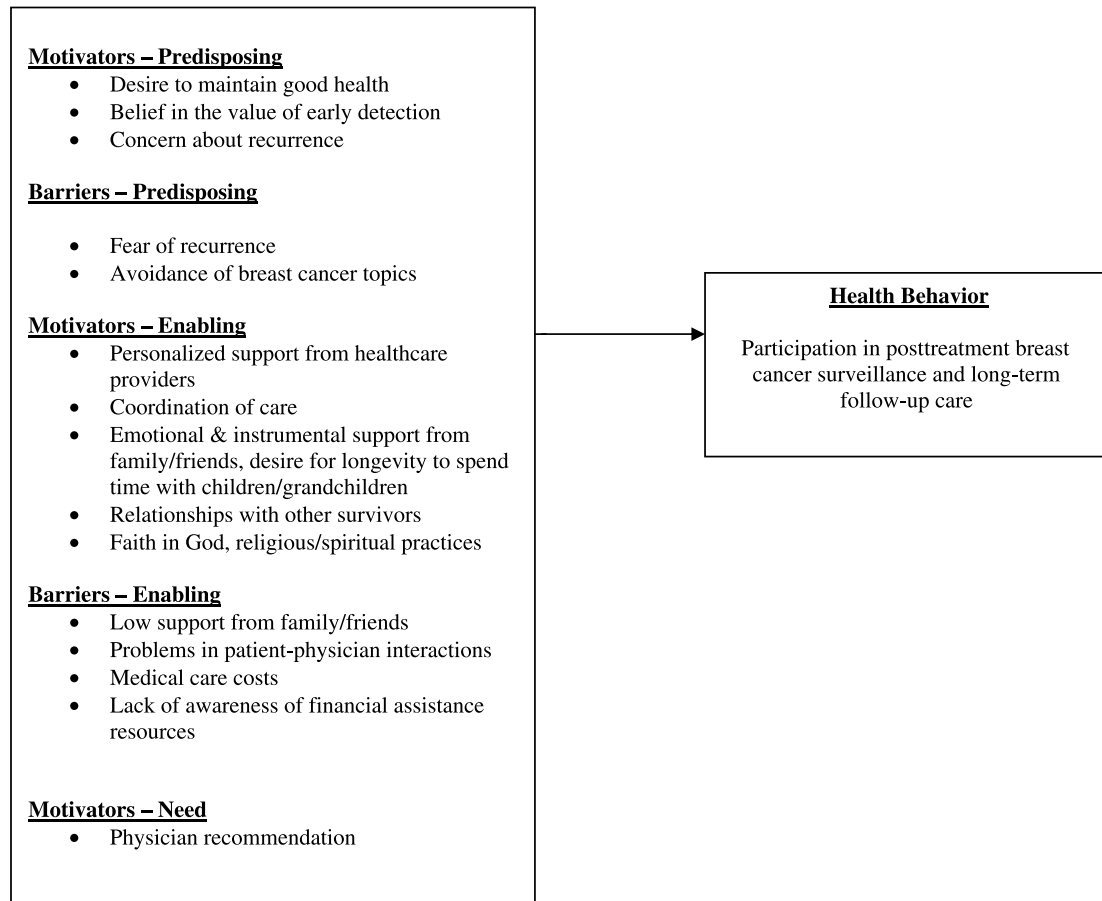


Figure 2 ■ Motivating and barrier factors categorized as predisposing, enabling, or need-related.

Although many participants reported that they were willing to participate in follow-up care and surveillance examinations based on their physicians' recommendations alone, they also reported that their physicians had a participatory style that involved them as a collaborator in their care.

Coordination of care was also a motivating factor. About half of the participants reported that the multiple physicians with whom they consulted also communicated with each other. Such communication appeared to bolster participants' confidence in the care received. Finally, nurses and health educators were also members of participants' care teams and, in some cases, provided information and support that was not received from a physician. For example:

In talking to the clinical trial nurse and having some kind of ongoing dialogue with her, I was able to ask her what were her recommendations. I felt that, um, I could have gotten that information from my doctor, but I didn't. But I was still able to get it.

FAMILIAL RELATIONSHIPS

The support of one's family was often endorsed as a motivating factor. Participants reported that they received both emotional and instrumental support from family members that encouraged them to obtain posttreatment follow-up care (eg, verbal expressions of support, accompanying participants to appoint-

ments). Participants also reported their strong emotional bond to family members as a motivating factor, specifically the desire to have a long life in order to spend more time with one's children and grandchildren. This is expressed in the following participant's statement:

My family, I can't even express. My children, my husband, my sister, they have all been there for me. What motivated me more to continue my check-up is because I have grandchildren. I would kind of like to see them grow up. So, I am very much motivated, myself, to get the proper care.

Follow-up care was also viewed as an opportunity to obtain more information about breast cancer and its outcomes. By doing so, participants believed they could keep their children and other family members informed about the disease.

RELIGIOUS OR SPIRITUAL FAITH

Almost all participants discussed faith in God as central to their lives posttreatment. In many instances, participants described a multidimensional and holistic view of breast cancer care that included medical, social, emotional, and spiritual foci.

My faith in God has played a big role in my follow-up care, even though, oh, um the doctors can take care of

the physical part of me but I need God for the spiritual part of me.

Other participants presented their faith as a form of coping, such that if a recurrence is detected, they felt confident that they could manage its challenges.

It plays a great part for me because, I am not saying because I pray and believe I will not get it again but if I get it again, my religious belief is that God, He knows that whatever He wants for me at this point, I am ready to accept. If it wasn't for Him, I wouldn't be here today. I think He steered me in the direction to finding it [the first breast cancer]. But if it happened to me, I could accept it a little more than the first time.

RELATIONSHIPS WITH OTHER BREAST CANCER SURVIVORS

Interactions with other survivors were reported as motivation to participate in follow-up care in 2 ways. First, the support received from other survivors was often reported as helpful.

If I am feeling a certain way, or if I am feeling low in spirit or something like that, I can speak to some of the other survivors who have gone through similar experiences. We help each other.

Relationships with breast cancer survivors was also a motivator because some participants felt it was important to be a role model to others by being particularly mindful of their health and care. This is demonstrated in the comment of a participant active in breast cancer education and outreach:

I also educate woman on breast health and I feel that I owe it to do it so then I have to follow up and take care of myself, so that my family and every one around me could see that it means something...you know, what I am saying is real and you know, I have to set an example.

TQ3b: What Factors Serve as Barriers to AA/AC Survivors' Follow-up Care?

Survivors also reported a number of barriers to follow-up care: fear of recurrence, low support from family and friends, lack of information about posttreatment follow-up care, and medical care costs. These barriers were also further categorized as predisposing, enabling, or need-related (see Figure 2).

FEAR OF BREAST CANCER RECURRENCE

Although concern about breast cancer recurrence may prompt participation in follow-up care, fear of being diagnosed again was specifically cited as a potential barrier to care. One participant described how fear may influence breast cancer survivors of African descent:

And sometimes some of them are scared to talk about their breast and some of them are fearful to go [for follow-up care] because they don't, like, if they had it [breast cancer] before they don't want to think they might have it again so they don't go, and things like that.

Some participants suggested that some survivors may blunt their worry and fear about a second breast cancer diagnosis by asserting that the breast cancer experience is "over" and of little relevance to one's life posttreatment. Toward this end, a survivor may avoid discussions about breast cancer and avoid those who were involved in her cancer care. For example:

I think also some people do want it to be over and you can bring some sort of finality to it if you are not seeing the same people as you did before.

LOW SUPPORT FROM FAMILY AND FRIENDS

Although 70% participants reported that support from family members was a strong motivating factor in obtaining follow-up care, 40% also reported mixed support from family and friends post-breast cancer treatment that was a potential barrier. A common theme was that significant others were uncomfortable with the participant's breast cancer experience or had not coped well with that experience. As one participant stated:

Actually, support from my family and friends was not that strong because they felt nothing and my family, some of them still can't come to terms with the fact that it [breast cancer] did happen to me.

In other instances, family and friends had different views of the controllability of breast cancer that informed their opinions about follow-up care. One Caribbean participant shared her experience:

My friends, well, it's a mixed thing. Some said nothing is wrong with me so I must not go and take the follow-up help. And some said go because, though I am a Christian, God said help those who help themselves. Yeah, so one side is telling me because I am a Christian I can't [be] sick. You know some people? And one side is telling me that because I am a Christian, I must do what I have to do.

LACK OF INFORMATION ABOUT POSTTREATMENT CARE

Participants frequently discussed lack of knowledge about the recommended follow-up care.

Yes, one of the things that I think is part of the problem is just lack of information. As I mentioned before, I have actually spoken to a couple of people, umm, you know in terms of the post situation... in terms of what I do and they were like, "Really? Why is all of that necessary?" And I was like, well this is what you should be getting, too. And they were like, "No the doctor said..." Like, one person had just finished chemo and radiation and said she wasn't seeing the doctor again for another year. And I was like, "You are supposed to go back." I said, "Call, do something," you know. So I think people are not as informed.

It was suggested that low knowledge was a function of patient-provider interactions in which survivors do not ask their physicians appropriate questions about care or are unassertive in obtaining this information.

Some people like to get information incrementally, on a need-to-know basis. And some doctors operate that way. You don't need to know and people accept that and I think that is a factor as well. In terms of...if you don't really know what you need to be doing or what you should be doing and you don't ask the right questions.

This response represents a belief reported by most participants that many AA/AC breast cancer survivors do not have access to adequate and up-to-date information about breast cancer care strategies.

MEDICAL CARE COSTS AND ACCESS

The cost of medical care was cited by almost all participants as a reason why AA/AC survivors may not be obtaining recommended follow-up. Costs were often linked to resources and it was reported that many survivors (1) are unaware of resources through which they might receive financial assistance or (2) are unable or unwilling to negotiate those bureaucratic aspects of those resources.

Close-ended Questions

Overall, participants reported high quality of follow-up care as indicated by responses to close-ended questions. Most participants agreed that, at follow-up visits, they get enough information about breast cancer recurrence at their follow-up visits (70%), their emotional and psychological concerns are addressed (70%), and that they feel reassured by follow-up visits (80%).

■ Discussion

The primary aim of this qualitative study was to explore the posttreatment breast cancer surveillance and follow-up care experiences of breast cancer survivors of African descent. Guided by the CRQ-TQ-IQ model, key informant interviews were conducted to address several broad areas. The first area focused on knowledge about posttreatment surveillance. Consistent with ASCO and NCCN guidelines, the most common recommendation reported by participants was an increase in physical examinations. However, participants did not report receiving follow-up care recommendations regarding mammography or other types of care, such as breast self-examination. It is possible that recommendations for other surveillance tests were made to participants but these recommendations were not associated with a comprehensive strategy of follow-up care. Also, given the various medical providers participants reported seeing for follow-up care, it is unlikely that all recommendations were presented in a single physician visit, thereby decreasing the likelihood that participants perceived the recommendations as comprehensive strategy. However, low awareness of such a strategy may not have had a significant impact on follow-up care participation, as indicated by the second area of inquiry in key informant interviews focused on participation in follow-up care. Most participants

were adherent to ASCO and NCCN guidelines with the majority reporting a mammogram in the past year and reported 2 or more physical examinations in the past year. Overall, rates of follow-up care participation were high among these participants, inconsistent with previous work reporting racial disparities in care between AA and white survivors.¹⁵

The third broad area addressed by key informant interviews focused on factors related to follow-up care. Participants in this sample reported a number of motivators of follow-up care that were consistent with the BMHSU and Baldwin's Afrocentric model (see Figure 2). For example, there were several motivating and predisposing factors identified that could be categorized as health beliefs as outlined by the BMHSU. These factors include the desire to maintain good health, belief in the value of early detection, and concern about recurrence. Barriers that were also predisposing were identified, including fear of recurrence and avoidance of breast cancer topics. Fear of breast cancer recurrence, in particular, may be an area warranting further investigation in the survivor population as previous findings related to cancer fear are mixed. Cancer-related fear is related to both a lower and higher likelihood of breast cancer screening in the general population.³⁷ In their review of this topic, Consedine et al³⁷ cited data suggesting that fear of screening components (eg, mammography pain and radiation) is more strongly associated with screening nonadherence compared with fear of screening outcomes and undifferentiated cancer fear. Although the participants in this sample focused primarily on the screening outcome of recurrence diagnosis, future research may examine the impact of different types of cancer fear in depth.

Motivating factors that were also enabling were identified and several were categorized as social relationship variables as outlined by the BMHSU. These factors include personalized support from healthcare providers, support from family/friends, desire for longevity to spend time with children/grandchildren, and relationships with other survivors. These factors are not only consistent with the BMHSU but also with Baldwin's African worldview construct. For example, the finding that significant others were reported as playing a positive role in participation in care is consistent with the assertion that collectivism, or belief in the primacy of the family or cultural group, is important to AA/AC women's health beliefs and practices.^{38,39} However, significant others were also reported as a barrier to care to the extent that friends and family members may avoid addressing a survivor's breast cancer experience or do not foster a supportive environment for a survivor to discuss her experiences. These results are supported by findings that, among women in the general population, low social support is associated with lower adherence to breast cancer screening guidelines.⁴⁰⁻⁴² Although the association between social support and follow-up care has not been explored among breast cancer survivors, studies have shown that social constraints, defined as social conditions that cause one to feel unsupported by their social network when they are seeking social support,⁴³ are associated with poorer psychological outcomes among cancer patients.^{44,45}

The relationship between social support, social constraints, and posttreatment follow-up care is one deserving further attention.

Support from physicians was also reported as a motivating and enabling factor in follow-up care. Participants were motivated by what they perceived as personalized attention and interest. Additionally, participants cited support from other types of healthcare providers, including nurses and health educators, who served as both primary and secondary sources of support and information.

One motivating, enabling factor not described by the BMHSU but consistent with African worldview is faith that God will help one cope with recurrence, as well as the use of religious/spiritual practices, such as prayer, in coping with the threat of recurrence. Previous work on cancer beliefs among people of African descent reveals belief in God's power to both cause and cure cancer, the recognition of spiritual and religious practice in cancer progression, and the categorization of cancer as "God's will."^{46,47} It is not surprising, then, that spirituality/religiosity emerged as a motivator of participation in follow-up care.

Motivators and barriers consistent with enabling resources include coordination of care, medical care costs, and lack of awareness of financial assistance resources. These findings are similar to general-population breast screening findings showing that prohibitive medical care costs,⁴⁸ lack of health insurance coverage,⁴⁹ and lack of access to screening and other healthcare services^{50,51} are associated with nonadherence to mammography. Finally, a need-related motivating factor in follow-up care was physician recommendation. Again, this is similar to findings of other works on breast cancer screening in the general population as physician recommendation is consistently associated with adherence to mammography among AA women.^{23,52}

Limitations of the current study must be acknowledged. First, the generalizability of results may be restricted because participants were members of established breast cancer survivor networks, either as lay educators or support group members. As such, they may represent a subset of AA/AC breast cancer survivors who are generally more motivated to seek out a range of medical, social, and psychological resources available to breast cancer survivors. Furthermore, these participants were fairly well-educated, with 40% of the sample reporting post-secondary education. Results based on mammography in the general population show that women with high school or college-level educations are more likely to have had a mammogram compared with women with less education.^{53,54} This may partially explain why participants in this sample generally reported high rates of participation in breast cancer surveillance and follow-up care. Due to the relatively high level of participant involvement in care, the full range of possible barriers to surveillance and follow-up care may not be described here. Future research in this area should address the following issues: (1) the recruitment of larger and more sociodemographically diverse samples of AA/AC survivors; (2) the identification of participants from a range of community-based and hospital- or clinic-based sources; (3) the use of other forms of qualitative data

collection, such as focus groups; (4) the translation of qualitative data into quantitative measures that may be validated; and (5) the inclusion of standardized measures to assess factors that have been supported by previous research.

Despite the study's limitations, this research represents one of the first attempts to understand and describe the surveillance and follow-up care experiences of breast cancer survivors of African descent. Ultimately, this line of research may inform surveillance-focused interventions, such as patient-directed interventions, that focus on educating survivors about the nature of recurrence, their risk of recurrence, and the recommended guidelines for surveillance and follow-up. Such interventions may also focus on informing survivors of the resources related to obtaining financial assistance for this care. Other interventions that may be considered are those that are physician-directed and focused on enhancing physicians' communication skills and interpersonal style which may lead to improved relationships with AA/AC breast cancer survivors and may motivate participation in care. Another type of intervention may be social network-directed. A survivor may benefit from interventions that engage family and friends by (1) educating them about the breast cancer etiology, treatment, and posttreatment follow-up care and survivorship issues; (2) exploring and processing their cognitive and emotional reactions to the survivor's diagnosis and treatment; and (3) providing coaching in cancer-related communication skills that may reduce a survivor's social constraints.

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